



**Fall Membership Meeting
Agenda
Wednesday, September 14, 2016
4:00-5:30pm
Lister Hill/Natcher Conference Center
NIH Campus
Conference Call-in #: 1-888-619-1583
Passcode: 715244 (*6 to mute/unmute your line)**

- I. Welcome and Introductions – *Janet Hieshetter, Chair*
- II. National Institutes of Health (NIH) Special Guests
 - A. Introduction of Joshua Gordon, MD, PhD, National Institute of Mental Health (NIMH) Director (pages 2-3) ***Invited not confirmed**
 - B. National Institute of Neurological Disorders and Stroke (NINDS) and BRAIN Initiative Updates - Walter Koroshetz, MD, NINDS Director ***confirmed**
- III. BRAIN Initiative Upcoming Events – *Samantha White, PhD, NINDS Science Communication and Coordination Specialist*
- IV. American Brain Coalition Innovation Initiative – *Janet Hieshetter, Chair*
- V. Advocacy
 - A. Advocacy Committee Report – *Matthew Rizzo, MD, ABC Board member and Advocacy Committee member*
 - B. Washington Update – *Lyle Dennis, Cavarocchi, Ruscio & Dennis Associates*
- VI. Treasurer’s Report – *Katie Sale, Executive Director on behalf of Louise Vetter, Treasurer*
 - A. 2016 Financial Report
 - B. Membership Dues Update
- VII. Action: Spring 2016 Membership Meeting Minutes – *Janet Hieshetter on behalf of Karen Ball, Secretary* (pages 4-8)
- VIII. Adjournment

NIH names Dr. Joshua Gordon director of the National Institute of Mental Health



National Institutes of Health Director Francis S. Collins, M.D., Ph.D., announced today the selection of Joshua A. Gordon, M.D., Ph.D., as director of the National Institute of Mental Health (NIMH). Dr. Gordon is expected to join NIH in September.

”Josh is a visionary psychiatrist and neuroscientist with deep experience in mental health research and practice. He is exceptionally well qualified to lead the NIMH research agenda to improve mental health and treatments for mental illnesses,” said Dr. Collins. “We’re thrilled to have him join the NIH leadership team.”

As NIMH director, Dr. Gordon will oversee the lead federal agency for research on mental illnesses. With an annual budget of approximately \$1.5 billion, NIMH supports more than 2,000 research grants and contracts at universities and other institutions across the country and overseas. In addition, the NIMH intramural research program supports approximately 300 scientists working on the NIH campuses. The mission of the NIMH is to transform the understanding and treatment of mental illnesses through basic and clinical research, paving the way for prevention, recovery and cure.

Dr. Gordon will join NIH from New York City, where he serves as associate professor of Psychiatry at Columbia University Medical Center and research psychiatrist at the New York State Psychiatric Institute. In addition to his research, Dr. Gordon is an associate director of the Columbia University/New York State Psychiatric Institute Adult Psychiatry Residency Program, where he directs the neuroscience curriculum and administers the research programs for residents.

Joining the Columbia faculty in 2004, Dr. Gordon’s research has focused on the analysis of neural activity in mice carrying mutations of relevance to psychiatric disease. The lab studies genetic models of these diseases from an integrative neuroscience perspective and across multiple levels of analysis, focused on understanding how a given disease mutation leads to a

particular behavior. To this end, the lab employs a range of neuroscience techniques including neurophysiology, which is the study of activity patterns in the brain, and optogenetics, which is the use of light to control neural activity. His work has direct relevance to schizophrenia, anxiety disorders and depression, and has been funded by grants from NIMH and other research organizations. Dr. Gordon maintains a general psychiatric practice, caring for patients who suffer from the illnesses he studies in his lab.

Dr. Gordon pursued a combined M.D./Ph.D. degree at the University of California, San Francisco. Medical school coursework in psychiatry and neuroscience convinced him that the greatest need, and greatest promise, for biomedical science was in these areas. During his Ph.D. thesis, Dr. Gordon pioneered the methods necessary to study brain plasticity in the mouse visual system. Upon completion of the dual degree program at UCSF, Dr. Gordon went to Columbia University for his psychiatry residency and research fellowship.

Dr. Gordon has been a member of the Hope for Depression Research Foundation's Depression Task Force since 2012, where he works collaboratively with this international group to define the neurobiology underlying depression and identify novel treatment targets.

Dr. Gordon's work has been recognized by several prestigious awards, including the Brain and Behavior Research Foundation – NARSAD Young Investigator Award, Rising Star Award from the International Mental Health Research Organization, A.E. Bennett Research Award from the Society of Biological Psychiatry, and Daniel H. Efron Research Award from the American College of Neuropsychopharmacology.

“I want to recognize and thank NIMH Acting Director Bruce Cuthbert, Ph.D., for his exemplary leadership of the NIMH over the past several months,” added Dr. Collins.



Spring Membership Meeting MINUTES
Thursday, March 17, 2016
Bethesda Marriott Hotel and Conference Center
Brookside Room
1:00-2:30pm

Attendance:

1. Janet Hieshetter, Chair
2. Robin Elliott, Past Chair
3. Mark Rasenick, Advocacy Committee Chair
4. Mike Amery, American Academy of Neurology, Board member
5. Bobby Heagerty, OHSU, Board member
6. Dr. Peter Kalivas, American College of Neuropsychopharmacology, Board member
7. Dr. Matthew Rizzo, American Neurological Association, Board member
8. Susan Stone, AllerganActavis, Board member
9. Nancy Bayerlein, AllerganActavis
10. Lynne Boyle, OHSU
11. Phil Cronin, Cure Alzheimer's Fund
12. Lisa Kaeser, National Institute of Child Health and Human Development
13. Dr. Walter Koroshetz, NINDS
14. Marian Emr, NINDS
15. Lana Shekim, NIDCD
16. Geoffrey Laredo, National Institute on Drug Abuse
17. Jenean McKay, National Ataxia Foundation
18. Mary Palafox, SARDAA (phone)
19. Heather Rieff, PhD, NINDS
20. Cynthia Rothblum-Oviatt, PhD – A-T Children's Project
21. Andrew Sperling, National Alliance on Mental Illness
22. Stuart Spielman, Autism Speaks
23. Matt Sturm, American Psychiatric Association (phone)
24. Katie Sale, Executive Director
25. Megan Anderson Brooks, CRD
26. Lyle Dennis, CRD

I. *Welcome – Janet Hieshetter, Chair*

Ms. Hieshetter welcomed members and guests, who introduced themselves.

Ms. Hieshetter thanked the American Society for Experimental Neurotherapeutics (ASENT) for hosting our meeting. ASENT's primary goal is to encourage and advance the development of improved therapies for diseases and disorders of the nervous system. As a reminder, ABC members are offered a free membership to ASENT.

The ASENT annual meeting is held through March 19 and contains very special programs, designed specifically for members and welcomed attendees. Registrants from academia, advocacy, government, and industry will discuss, address and advance the science of

Neurotherapeutics. From basic science to clinical trials to discussions about the newest therapies, the ASENT Annual Meeting provides a forum to connect, to network and to participate in continuous learning and discovery.

II. Special Guest: NINDS and BRAIN Initiative Update

Ms. Hieshetter introduced Dr. Walter Koroshetz, Director of the National Institute of Neurological Disorders and Stroke, who we are honored to have as our special guest. This is the first time he's with us formally in his role as Director.

Dr. Koroshetz began by articulating the importance of a coalition such as the ABC since it is more important than ever for our organizations to speak with one voice and send the same message on Capitol Hill. He has been told by numerous members of congress that they want groups to come together and align their messaging.

Dr. Koroshetz indicated that after NIH having a flat budget for 12 years, they are excited that the budget has increased by 6%. This increase is targeted to specific areas and it's actually a 3.9% for institutes. It includes a \$350M for Alzheimer's research. The BRAIN Initiative has gotten additional funding, as well. In the initial BRAIN 2025 report, it was noted that by 2025, BRAIN would ideally like to see funding at \$190M. BRAIN is currently funded at \$150M, which is getting closer to this number. BRAIN is meant to focus on new technologies and tools in different areas in neuroscience, and is not disease specific. They are awarding grants to gain an understanding of circuitry and what goes wrong when the brain is not working, it is about understanding pathology. It was asked what was being done for the Autism Spectrum, and Dr. Koroshetz noted that imaging and the ability to get better data would change the game for Autism and many other brain diseases. The kinds of things the BRAIN Initiative is working on will be game changes for patients if they come through.

Geoff Leorado explained the ABCD Study (Adolescent Brain Cognitive Development) that NIDA and other agencies are contributing that is a 10-year look at substance abuse of 10K subjects. More information on this Project can be found at: www.drugabuse.gov/related-topics/adolescent-brain/longitudinal-study-adolescent-brain-cognitive-development-abcd-study.

Dr. Koroshetz indicated that the Neuroscience Blueprint, in which the neuroscience institutes have come together, is set to expire; however, most agencies have agreed to the importance of continuing to work together.

Dr. Koroshetz indicated that the company contribution and collaboration around BRAIN is not great; however, there is great collaboration with the other federal agencies and foundations, as well as international agencies. A BRAIN Alliance is being formed to act as a communication tool to various stakeholders.

It was agreed that it would be important for the ABC to provide an update on where BRAIN is today, and provide additional resources that our members can disseminate. Katie Sale reminded members that the ABC has an extensive BRAIN Initiative page on the ABC's web site, and will add a link to the "BRAIN 2025 Report" and the NIH book that was put together following this report.

The question of what the advocacy community could be doing was raised. The AAN generated a "Dear Colleague" letter signed by Members of Congress Earl Blumenauer, Cathy McMorris

Rodgers, Chaka Fattah, and Tim Murphy, which the ABC circulated as an action alert encouraging our members to contact their members of congress to sign on to this letter.

The NIH is looking at the impact of research and has a section on their web site where they're sharing stories of impact through social media. The ABC will share this with the membership.

Dr. Koroshetz concluded by saying he welcomes any questions at any time and looks forward to continuing conversations with the ABC.

- A. Walter Koroshetz, MD, Director of the National Institute of Neurological Disorders & Stroke
 - B. Question & Answer Session
- III. Advocacy
- C. Advocacy Committee Report – *Mark Rasenick, PhD, Advocacy Committee Chair*

Dr. Rasenick indicated that last week, the Senate HELP Committee released a draft of its bipartisan mental health bill, which addresses the provider workforce shortage and care access issues and makes changes at the Substance Abuse and Mental Health Services Administration. The bill, crafted by Chairman Lamar Alexander and ranking member Sen. Patty Murray, would require SAMHSA to hire a chief medical officer and report to Congress every two years on its activities. It also requires HHS to establish a committee dedicated to work on serious mental illnesses. The ABC is sending two separate letters to the E&C and Senate thanking them for drafting such a bill.

The Senate HELP Committee passed the Advancing Research for Neurological Diseases Act of 2015. Dr. Rasenick thanked the great advocacy work was done by two ABC members, the Parkinson's Action Network and the National MS Society in advancing the bill. The ABC supported the bill by signing on to letters, sponsoring briefings, and attending meetings with members of congress.

Howard Hughes Medical Institute (HHMI)'s film production company has produced a new documentary film on the current state of clinical trials for potential Alzheimer's disease therapies. The documentary will air on NOVA on PBS this spring. The film not only traces the history of Alzheimer's disease research from its roots to the cutting edge research being done today, it also follows several clinical trials testing potential treatments for Alzheimer's in patients across multiple countries over the course of several years. The film aims to shed light and educate the public on how complex and expensive these types of clinical trials can be and why so many have failed in the past. As new classes of treatments go through the various phases of clinical testing, researchers share their insights and sources of hope for the future of Alzheimer's disease research. To create interest in the film, the Congressional Neuroscience Caucus has agreed to show the film and we're working on a date to do so. The ABC is a sponsoring partner along with Cure Alzheimer's Fund and the Society for Neuroscience.

Dr. Rasenick updated members on an upcoming Congressional Neuroscience Caucus event scheduled for April 27. Speakers include: Bill Griesar, PhD and Jeff Leaker, MFA. Bill Griesar teaches neuroscience at WSU Vancouver, Portland State University, and OHSU. Jeff Leake is an instructor and outreach coordinator at WSU Vancouver. They will discuss NW Noggin. NW Noggin prepares students to confidently explain topics in neuroscience using art projects and activities in a wide variety of formal, informal, urban, and rural settings. Students from Washington State University Vancouver (WSUV), Portland State University (PSU), Oregon

Health & Science University (OHSU), and the Pacific Northwest College of Art (PNCA) have presented in schools, theaters, art museums, conferences, the symphony, homeless youth centers, breweries, and velocipedal taprooms. They plan to have brains on hand and have this be more of an educational opportunity for staffers and guests. We are partnering with the Phillips Collection who is hosting Seeing Nature, landscape materworks from the Paul G. Allen Family Collection.

Marian Emr indicated that Santiago Ramon y Cajal's exhibit is displayed at NIH. There might be an opportunity for folks to visit the NIH campus and this exhibit during this outreach. Ms. Sale and Ms. Emr will work together to work out logistics.

OSTP at the White House suggested that the ABC contact some universities and suggest they host a patient advocacy brain day to engage university researchers and clinicians with patient advocacy groups. Katie Sale will begin working with the ABC's affiliated universities in encouraging them to host a patient advocacy day at their university.

This week, the ABC encouraged members to reach out to their US House members and urge them to sign on to a bipartisan "Dear Colleague" letter supporting increased funding for the BRAIN Initiative at NIH. This letter was signed by Earl Blumenauer, Chaka Fattah, Cathy McMorris Rodgers, and Tim Murphy.

The ABC has signed on to the following letters:

1. Ad Hoc Group Steering Committee sign on letter to leadership of the House and Senate Appropriations Committees thanking them for the \$2 billion increase in NIH funding included in the FY 2016 omnibus spending bill.

2. Coalition for Health Funding sign on letter to leadership of the House and Senate Appropriations Committees asking for strong 302(b) allocations.

D. Washington Update – *Lyle Dennis, Partner; Megan Anderson Brooks, PhD, Cavarocchi, Ruscio & Dennis Associates*

Mr. Dennis began the report from CRD Associates by discussing the current climate in Congress. He noted that the bi-partisanship of Congress has been exacerbated this year by the Presidential election, the dispute over the vacancy on the US Supreme Court and the perception that the economy is weak.

These divisions create problems for carrying on the routine business of the Congress, such as passing a budget resolution and appropriations bill. A budget agreement was reached a few months ago on a top line number for FY2017 spending; however, some members are trying to re-visit the issue and reduce funding further. This has held up any progress on moving the 12 individual appropriations bills, as the subcommittees need to know how much money they have available in order to craft their bills.

While the budget caps are continuing to restrict opportunities to increase funding, there have been strong statements made by the chairs of both the House and Senate subcommittees that additional NIH funding is a very high priority. However, given the paucity of days in the legislative schedule, it may not be until the lame duck session in November that funding issues are brought to a conclusion.

Megan Anderson Brooks addressed the 21st Century Cures Act and the medical innovation bills being considered in the Senate. She reminded members that the Cures Act passed the US House of Representatives in July of last year. She explained that the Senate Committee on Health, Education, Labor, and Pensions has held two markups on a list of individual bills and will hold another markup on April 6th. During the first markup, the Committee approved S. 849 The Advancing Research for Neurological Diseases Act, which ABC has supported. She relayed that it was unclear if the bills were going to be packaged together or not. Dr. Brooks said that Democrats are indicating that they will not support an innovation package if funding for NIH and FDA is not included. Sen. Elizabeth Warren (D-MA) introduced the National Biomedical Research Act which would provide an additional \$5 billion per year in automatic funding that would be split between NIH and FDA. The funding would be used for large scale research projects like the BRAIN Initiative and the Precision Medicine Initiative. Chronic disease research would also be eligible to receive funding. Dr. Brooks said that it was unclear whether the Committee would markup the bill or not.

Dr. Brooks also discussed mental health legislation. There has been a partisan division of support for H.R. 2646 Helping Families in Mental Health Crisis Act and since being approved by the House Energy and Commerce Health Subcommittee, the bill has not moved. The Senate HELP Committee marked up and approved a companion bill, S. 2680 Mental Health Reform Act. Dr. Brooks relayed that the bill is being considered by some to be a narrow consensus document and that some of the tougher issues will be considered on the Senate floor. The bill does not include language that the ABC Advocacy Committee has discussed related to creating a new Assistant Secretary of Mental Health and Substance Use Disorders at HHS. The Advocacy Committee is working on letters that will be sent to both the House and Senate committees on this issue. (These letters were sent on 3/22/16.)

Dr. Brooks commented that pay-fors will be a factor for passing these expensive large legislative packages on medical innovation and mental health.

IV. Treasurer's Report – *Louise Vetter, Treasurer*

Ms. Sale, on behalf of Louise Vetter, indicated that we are on track with finances, and have a tight budget of less than \$250K. She will be sending out dues invoices soon and encourages members to contribute in a timely manner.

V. Action: Fall 2015 Membership Meeting Minutes – *Karen Ball, Secretary*
(pages 2-9)

Motion to approve the Fall 2015 Membership Meeting minutes by Dr. Matt Rizzo; seconded by Dr. Rothblum-Oviatt, approved by the membership.

VI. Other Business

Ms. Hieshetter informed members that we are excited to be teaming up with the National Institute of Neurological Disorders and Stroke in hosting our Fall ABC Membership Meeting in conjunction with the NINDS Nonprofit Forum, which is scheduled for September 13-14, 2016 in Bethesda at the NIH campus. This Forum provides an opportunity for nonprofit leaders to network with colleagues and to engage in discussions with NINDS staff. We will be in touch soon with exact dates for the Forum and the Fall Membership Meeting.

VII. Adjournment